

Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study

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See editorial
by Roberts and
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Abstract

Objectives—To identify and explore difficulties parents experience with acute illness in young children and the information they seek to help them.

Design—Qualitative study using semi-structured one to one and group interviews with parents of preschool children.

Setting—Disadvantaged inner city community.

Subjects—95 parents of preschool children.

Results—Parents felt disempowered when dealing with acute illness in their children because of difficulties making sense of the illness. Central to parents' difficulties were their experiences of inadequate information sharing by their general practitioners and variations in their doctors' decisions and behaviour. Disparity between parents' beliefs and expectations about illness and treatment and professionals' behaviour further frustrated parents' attempts to understand illness. Parents expressed a need for a range of accessible and specific information to support them through their negotiation of children's illness.

Conclusions—Communication with parents requires greater recognition of parents' difficulties. Professionals have considerable potential to empower parents by sharing more information and skills. Such information should be consistent and address parents' concerns, beliefs, and expressed needs if this potential is to be realised.

Introduction

When a child becomes acutely ill, parents' concerns may be influenced by their perceived degree of control in relation to the perceived threat of an illness.¹ Information and education may enhance parents' sense of control and inform their perceptions of threat. However, the provision of information to parents about children's illness has met with only modest success.²⁻⁵ The impact on parents' knowledge and use of primary care services has proved disappointing,^{4,6} and some information may worsen parental anxiety.⁴ Although parents seem to use and value information, some question its relevance and find answers lacking to common queries.⁷ Parents are also reluctant to follow advice that clashes with their beliefs and established practice.⁸ Information is almost invariably defined by professionals with little or no consultation with parents. Previous research has emphasised the practical realities of caring for young children and described parents' beliefs and behaviours,⁹⁻¹¹ but little is known about parents' perceptions of what may help them when their children become acutely ill. In this study, which formed part of a research project to develop information for parents with their participation,¹ I identified difficulties parents experience and their information needs when faced with acutely ill young children.

Subjects and methods

The methods used and the sample interviewed have been described in detail in the accompanying paper.¹ Semi-structured, one to one interviews were conducted with a purposeful sample of 32 parents living in a disadvantaged community who had at least one child

under 5 years old. A further 63 parents attending three parent and toddler groups participated in focus group interviews. The interviews explored parents' experiences and difficulties coping with ill young children and were audiotaped and transcribed. Data collection and analysis used grounded theory methodology.¹² Data gathered concerning information needs were analysed using manifest content analysis.¹³

Results

The dominant theme that emerged in the analysis was of parents feeling relatively disempowered when dealing with acute illness in their children. They encountered difficulties making sense of their child's illness. Their experiences of seeking advice from professionals could leave them feeling uncertain and uninformed. The disparity between parents' beliefs and expectations about illness and treatment and professionals' behaviour further frustrated parents' attempts to understand their children's illness. These factors could act as sources of dissatisfaction and sometimes disharmony in the relationship between parent and doctor.

"IT'S JUST A VIRUS"—ASSESSMENT AND INFORMATION SHARING BY DOCTORS

Parents were generally confident about recognising whether their child was becoming ill. They used combinations of behavioural and symptomatic clues assessed against any deviation from what was normal for their particular child. There was far more uncertainty about deciding what was wrong and if a problem was significant or serious. Parents drew on family, friends, or the local pharmacy for guidance but usually consulted, or were advised to consult, their doctor when an illness was causing them concern.

Respondents were curious to know how doctors evaluated an ill child. They felt excluded from the apparent mystique of the professional's assessment. The commonest example was seeking advice about a child's cough when they feared infection "on the chest" because the child's chest sounded, and even felt, "rattly." However, the doctor would pronounce the lungs "clear" on examination despite apparent evidence to the contrary. Parents would then find it difficult to question the doctor's authority and were left feeling silly for worrying or still perplexed by the problem. Parents also often wondered how doctors determined the severity of illness in babies (box 1).

Box 1—The mystique of the doctor's assessment

"When the little one's sounding raspy and wheezy...the doctor sorts of puts the stethoscope on and says, 'Well, it sounds clear,' but I mean you know yourself there's something wrong" (Parent 15)

"She was bringing back her bottles and I thought she was really sick...He came and took one look and said she was OK, but how did he know?" (Parent 24)

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Box 2—Parents on doctors' diagnosis of viral illness in their child

Extract from group interview

Parent 2: They think they make you feel better saying it's a virus...but they make you feel worse

Parent 7: When they say it's a virus, I mean what kind of virus? Just where does it come from?

Parent 1: You're none the wiser how they got it, what you can do, how long it will go on...

Parent 5: You feel you're no further forward...you just have to accept it if they don't explain further, I would like to know...

Parent 2: It's an unknown thing to a doctor, they can't pinpoint it, they don't know really...

Parent 1: I feel a bit annoyed really because you think they've studied for years to learn that and I haven't studied at all, you feel dissatisfied as if you wanted to hear something more...you just wish that everything was clean cut

Parent 4: At least if you really knew what it was then it's easier to cope with
(Group 3)

Participants thought that they received insufficient information or explanation from their general practitioner about what was wrong. The most common example was a child being given a diagnosis of a viral or self limiting illness. Being told their child had a virus or bug was often confusing, provoking anxiety rather than reassurance and sometimes anger. Parents regarded the label of virus or bug as unsatisfactory because it seemed too vague: it did not offer them a sense of being in control or define what was wrong with their child. Some parents believed that a viral explanation was offered when the doctor was unsure about the diagnosis (box 2).

PARENTS' EXPERIENCES AND BELIEFS ABOUT TREATMENT

Parents' difficulties about what was wrong with their child were enmeshed with their understanding of management of the illness. Apparent variation in doctors' decisions about prescribing antibiotics created confusion for parents, frustrating their ability to make sense of the illness and learn for the future. Many had experience of receiving antibiotic treatment routinely—for example, when their child had a cough or sore throat—and then encountered conflicting behaviour from the same or a different doctor. Such inconsistent messages left parents baffled by how a doctor decided whether to prescribe, and they occasionally detected indecision among doctors themselves (box 3).

Parents' beliefs about when antibiotics should be prescribed did not relate to the cause of the illness but were grounded in their notions of severity of the illness and the impact the illness had on their child, particularly

Box 3—Conflicting behaviour in doctors

"The doctor said it was a virus and needed no treatment and then a few days later the other doctor gave her the antibiotics" (Parent 10)

"She'd been ill with this awful cough for two weeks, the doctor said it was a virus and eventually she gave me antibiotics and said, 'They probably won't work anyway.' And I thought, 'Am I being stupid or something? Why did she give them to me?'" (Parent 9)

their child's behaviour—for example, sleeping pattern—or if their child seemed to be in pain. Some believed that symptomatic treatments such as paracetamol or cough syrups had the same mode of action as antibiotics but that antibiotics were more potent so any illness would improve earlier with antibiotic treatment. Similarly, perceptions about disadvantages of antibiotics were not related to the cause of an illness. They were usually expressed as a belief that too many courses of antibiotics would harm their child's immunity to future illness or result in antibiotic treatment being less effective when their child had more serious illness—that is, their child would become resistant to the effects of the antibiotic.

RELATIONSHIP BETWEEN PARENT AND DOCTOR

Most parents experienced feelings of helplessness when faced with their child suffering from an illness: they strongly wanted to be actively treating their child to diminish these feelings. This was often tied to expectations that their child should be prescribed antibiotics and disappointment and frustration when this did not occur, even among parents who seemed to most readily acknowledge the self limiting nature of most children's illness. Some parents perceived the withholding of antibiotics as illogical, and this was a common source of disharmony or even conflict with the doctor. A prescription for antibiotics seemed to represent more than a decision about treatment: it was a way of helping some parents to cope and an indication that their concerns had been taken seriously by the doctor. Some respondents thought that there had been a historical change in doctors' prescribing habits, with doctors less willing to prescribe than in the past. They thought that this might be because doctors increasingly had to consider costs (box 4).

Box 4—Parents' expectations of antibiotics from the doctor

"I feel as though we've got enough problems to contend with, surely it's better to get him feeling well quicker than delaying, even if you know he could get better on his own" (Parent 17)

"She had a really bad cough and I asked for antibiotics and the doctor didn't really want to give me them...it was as if she begrudged giving me the antibiotics" (Parent 3, group 3)

"You just get palmed off with Calpol... you sort of feel let down...disheartened...sometimes you feel as though maybe they're not actually listening to what you're saying" (Parent 21)

"They used to give them [antibiotics] in the past, it just seems to be now they can't with the budget...if it's not going to make them seriously ill they just let it run its course" (Parent 22)

Parents faced dilemmas about whether to seek their doctor's advice. There was a strong desire to share responsibility for assessment of their ill child with a professional, but parents often worried or felt guilty that they might be bothering the doctor unnecessarily. Although parents sought more information from their doctors, they could feel uncomfortable or lack confidence in making their real concerns clear to the doctor. They were wary of questioning professionals' authority and conscious of pressures on the doctor's time. Parents described their "no win" dilemma when deciding to seek advice about an ill child and how their

Box 5—Parents' no win situation

"There's a few times I've went to ask if the doctors thought it was something and I've held back because...they may think I'm trying to tell them their job...and then it's still on your mind" (Parent 2A)

"If you bring them early they say, 'Leave it a few days and see,' if you wait they say, 'You should have brought them sooner'...you feel stupid...you can't win" (Parent 9)

confidence could be undermined by apparently well intentioned remarks from the professional (box 5).

INFORMATION SOUGHT BY PARENTS

Parents expressed a need for more information about children's illness. Advice about the management of common symptoms was insufficient. They sought explanation and detail that was specific and practical to help them make decisions about the likely cause of an illness, how to assess severity, and when to seek professional advice. They wanted to know of any implications of the illness or its treatment and the potential for prevention in the future. Most thought that being more informed would reduce rather than increase their anxiety (box 6).

Box 6—Feeling uninformed

"It's the not knowing what it could be—how to tell—that's what panics me, if I was told what to do, shown what to do and how to do it, I would feel I could manage much better" (Parent 6, group 1)

"You come out [of the surgery] wondering is there something you could do to prevent it happening again and the causes and effects...Is there anything else I need to look out for?" (Parent 20)

Participants who had books on preschool children found that the authors tended to concentrate on child development and to give general advice to "call your doctor if you are unsure." This guidance failed to increase their confidence or answer their questions—for example, what would a doctor seek in assessing a young baby, a noisy chest, or a rash? Parents thought that sharing common experiences of dealing with illness in young children would be useful in future guidance and make it more relevant, particularly for inexperienced parents. They suggested including parents' hints for nursing sick children, and the importance of looking after your own health as a parent. The principal areas parents wished to know more about reflected the difficulties they described (box 7).

Box 7—Parents' information needs

- How to gauge the severity of illness
- How doctors assess illness
- When to seek advice
- The nature of viral illness
- How over the counter medicines and antibiotics work
- The nature of rashes
- Learning about other parents' experiences

PRESENTATION OF INFORMATION

Participants emphasised the importance of information being accessible. They had usually learned more specific information about illness from the media: from parenting magazines, television dramas, or publicity campaigns. The most popular suggestions were for an illustrated booklet with photographs and videos, which they thought would be more effective if shown in discussion with a professional. Respondents thought that parents would be most receptive at antenatal clinics in general practice, baby clinics, and toddler groups. Although parents suggested information should be free of jargon, they were keen that it should not omit important technical information that would facilitate their understanding.

Discussion

This study has found that both a lack of information and experiences of interactions with health professionals disempowers parents trying to understand acute illness in their children. This was a qualitative exploration of the experiences of a largely disadvantaged, white English speaking group of parents. Methodological strengths and limitations of this research have been discussed.¹ Further research is planned to establish whether the results are generalisable to other parents of differing backgrounds.

COMMUNICATION WITH PARENTS

Parents' problematic contacts with professionals present challenges for improving doctor-parent communication. General practitioners have important opportunities to provide information consistently and face to face. Moreover, information is often all the professional may have to offer. Labelling an illness as viral may not be helpful unless a parents' beliefs and understanding are explored and discussed with appropriate explanation. Parents' lack of confidence asking their real questions underlines the importance of trying to clarify concerns and treat lay knowledge seriously. This has been emphasised before¹⁴ but fails to feature routinely in doctor-parent contact.

Parents' understandable desire to pursue an active course of management may reflect not only erroneous beliefs about viral illness and treatment but also frustration at feeling unable to maintain control¹ of their child's illness. It may also reflect increasing expectations of a cure from health services. It may be particularly important to recognise parents' possible frustration when a self limiting illness is diagnosed.

Confusion arising from doctors' inconsistent prescribing of antibiotics suggests the need for unambiguous and consistent messages from professionals to parents about when these drugs are indicated and greater transparency about what may be affecting decisions to prescribe. This may not be easy, given the considerable variation in doctors' prescribing behaviours and the many factors underlying them.¹⁵ Professionals might usefully examine their own beliefs and what influences their prescribing. Research exploring doctors' management of illness in their own children could also prove illuminating.

UNCERTAINTY AND CONFLICT IN DOCTOR-PATIENT RELATIONSHIP

Parents' perceptions that a diagnosis of a virus or bug implied uncertainty on the part of the doctor is unsurprising, given parents' experiences of variation in professionals' behaviour. It might reflect the way in which explanations are offered or their difficulty in acknowledging such illness as self limiting. The lack of a specific treatment may diminish their perceived degree of control.¹ Diagnosis of a viral illness is usually by exclusion with an inevitable degree of uncertainty, to

which parents may be sensitive. This highlights the tensions that may arise for both parents and professionals if greater sharing of esoteric knowledge and skills with parents is accompanied by the difficulties of tolerating and sharing uncertainty. Professionals' dilemmas about diagnosis, waiting and seeing, and prescribing antibiotics may be surprisingly similar to parents' experiences.

Parents were strongly influenced by a sense of responsibility to act as competent parents and the fear of overwhelming guilt should they fail to do so.¹ The care of ill children is undeniably a moral issue and parents are judged by their actions. The seeking of professional advice creates the potential for conflict between parents needing to show that they are adequate parents in accordance with society's standards and acting appropriately according to professional standards (not bothering the doctor for trivial illness). Parents acknowledge their lack of medical skills but at the same time maintain that doctors expect them to be competent in this area. As parents they are in a no win situation. Greater awareness that these issues lead to inequality in the parent-doctor relationship may help to reduce the potential for disharmony between parents and professionals. This parallels work that has shown that conflict in doctor-patient interactions lies in doctors' contradictory expectations of patients' behaviour, which place patients in a double bind.¹⁶ Doctors believe that patients should use their judgment about when to seek medical advice but later expect patients to abandon any claims to expertise in the consultation and defer to the doctor's judgment.¹⁶

SHARING INFORMATION

The ability to cope with threatening events may be increased if those events are predictable. This study has identified information sought by parents that may diminish the ignorance and feelings of impotence parents experience, enhance their sense of control, and modify their perceptions of threat posed by an illness.¹ Parents' suggestions about the kind of specific information they need contrasts with that usually defined and presented to them: they sought more than simple advice about management of common symptoms. Information should be developed according to parents' perceived needs and incorporate parents' skills and experience, as the respondents in this study suggested. Education and advice must also recognise and address parents' commonly held beliefs about viruses, self limiting illness, and antibiotics and their key concerns about fever, cough, and meningitis.¹

Respondents' enthusiasm to learn more, particularly about assessment of illness and its severity suggests that sharing such skills may be worth while. A crucial issue is whether the appropriate sharing of uncertainty in decision making by doctors will facilitate parents' education and understanding or create further difficulty. The education of parents has obvious implications for professional time. This obstacle might be overcome using parents' suggestions—for example, developing educational packages of written and audiovisual material for use by parents at home or in interactive groups at general practitioners' surgeries in discussion with the practice nurse, health visitor, or doctor during baby or antenatal clinics. Strategies might explore models of young mothers' participation in discussion groups in general practice,^{17 18} and a practice nurse providing education about minor illness may also be feasible.¹⁹ Although parents complain that they receive too little or conflicting information, doctors may be wary of giving information that may cause anxiety. People differ in their style of coping: some may wish to be better informed than others. Information and education for

Key messages

- Parents trying to understand acute illness in their children are disempowered by their experiences of inadequate information sharing and variation in the behaviours of doctors
- Greater recognition of parents' difficulties may help to reduce potential disharmony between parents and doctors
- Attempts to share greater and consistent information may empower parents and should be sensitive to parents' concerns, beliefs, and needs
- Tensions may arise for both parents and doctors if greater sharing of knowledge is accompanied by difficulties in tolerating and sharing uncertainty

parents is probably best made available to those who want it rather than disseminating it to everyone. However, there seems to be a good case for targeting parents who have particular difficulties in managing usbill children.²⁰ This study suggests that professionals could do more to empower parents. The degree to which professionals feel able to relinquish their monopoly on expert knowledge and skills poses a further challenge.

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